Uniquely Human:
A Different Way to See Autism and Create Pathways to Success
Presenter: Barry M. Prizant, Ph.D.,
Childhood Communication Services & Adjunct Professor Brown University
Moderator: Clay Whitehead Co-CEO and Co-Founder, PresenceLearning

June 16, 2015

Learning Outcomes

• Helping children with autism succeed
• Change perceptions and practices based on understanding the uniqueness of students with ASD, and many practical ways we can help students with autism achieve both in school and in life outside of school.

Why “Uniquely Human”?

• Behavioral patterns/reactions of children with ASD have been misunderstood, and even dehumanized
• Even deep interests and strengths have been referred to as obsessive and perseverative, leading to attempts to reduce or eliminate them
• At best, many behavioral patterns have been judged inappropriate without asking WHY?
• Family experience of ASD - described primarily as a tragedy – not accurate
• A behavioral perspective dominates, but we also need a developmental, person-centered perspective
• Essential to provide a more accurate perspective for success in schools
Focus on Four Issues
1. understanding the behavior of students with ASD - their challenges and experience
2. understanding the experience of parents - their challenges and experience
3. debunking the belief that ASD a tragedy for the child and family
4. debunking the belief that ASD is only within the child

ASD is a shared human experience
This shared experience presents
1. Challenges
2. Potential for growth for all students and the school community

Common descriptions of the behavior of students with ASD
- non-compliant/stubborn
- manipulative
- perseverative or rude
- bizarre/avoidant
- defiant/challenging
- obsessive/self-stimulatory
- non-functional
- meaningless/relevant
- pervasive
- non-communicative

Consequences:
Misunderstanding behavior of students with ASD
- Little need to understand, support or to empathize, just to categorize as desirable or undesirable
- It’s the student who needs to change
- Reflective practice (impact of our beliefs and behavior) is not a priority for professionals and support staff
- If other students don’t understand, higher likelihood of bullying

What we’ve learned from experience and research:
- There is no such thing as autistic behavior - it is all human behavior
- Behavioral patterns can best be understood as:
  - reactions to confusion, stress and anxiety
  - are often attempts to communicate and cope
- WE NEED TO ASK WHY?
Essential steps to increase understanding & better serve students

- **Build Understanding**
  - Reframe our understanding of schools, inflexible, "controlling" behavior, obsessive interests
- **Respond with compassion**
  - As why a student does what we observe, try to understand his/her perspective
- **Express Appreciation**
  - Given the neurologically based challenges (social, sensory, etc.), let’s look at what is going right and appreciate how hard & may be for a student
- **Provide Support**
  - For on the side of providing appropriate interpersonal and learning support

Actions that schools can take

- Disability and autism awareness programs
- Students with ASD talking about their autism
- Parents who feel comfortable talking to students and staff
- Adults with ASD consulting to schools

Parents of children and persons with ASD are often misunderstood and at times, have gotten a “bum rap”

**Descriptions of parental behavior:**
- Challenging
- Aggressive
- Non-compliant
- Unrealistic
- Disengaged
- Overly protective

Consequences: Misunderstanding of parental responses

- Negatively impacts collaboration
- Professionals don’t learn to listen well
- Judgmental attitudes prevail
- Disproportionate focus on problems rather than successes with parents.
- Litigation more likely

What we’ve learned from experience, research, and from parents:

- They are often doing the best they can – “juggling a million balls”
- They too often feel judged
- If they don’t follow through, they may not understand how to, don’t have the time or are dealing with other issues in the life of the family
Steps to increase understanding and better serve families

- Build understanding
  - Stress of uncertainty, try to understand where the family is on their journey, what previous experiences have they had both positive and negative, and what are their hopes for the future.

- Respond with compassion
  - Let parents express their feelings. Try to understand their perspective (i.e., why a parent does what we observe, try to understand his/her perspective often, they are doing the best they can for their child, all the social, political, economic, and personal stresses)

- Express Appreciation
  - Given the neurologically-based challenges (social, sensory, etc.), look on what a going light in the family and appreciate how hard it may be – appreciate what they do for your student and their family

- Provide Support
  - Let them be heard, show respect, help parents prioritize what is most important, validate their situations about what is best for their child. “How can I help? What’s most important to you for us to work.”

Actions that schools can take

- Staff training in family-centered practice and communicating with parents
- Full-time staff with expertise in family systems
- Support parent advisory committees
- Special supports for families – after-school coverage for “parents night out”

Myth

ASD is nothing more than a tragedy for the child and family

"Blind Tom"
Thomas Wiggins 1846-1908

"Here is a monstrosity... the soul of some unfortunate defunct musician misbehaving on earth".
"I think of him marvelously gifted by nature. He is an angel sent by God"

"Autism is a lost, hellish world"

David Kirby, “Evidence of Harm” (2005)

"I employed the term “holocaust”... as I struggled to find an expression to convey the catastrophic tragedy of autism which has now destroyed the lives of over 20 million children and shattered their families."

Robert Kennedy Jr. - Quote (4/7/09)
Vs. the notion of autism as a tragedy –

Quotes from people with ASD & parents:

“Welcome to our little corner of the world. Some call it autism, others call it disorder and syndrome. I happen to call it hope, beauty and fascination.”

- Mother of Angel, 9 years old from Hungary

“Autism is not a disease; it is a way of being. There is no cure, nor is there a need for cure. There is, however, a need for knowledge and adaptation on the part of Aspergians and their families and friends.”

- John Elder Robison, adult with ASD

“The people who have been most helpful to us are those who do not take away our hope. We have learned to keep away from the ‘dooms and glooms’ crowd.”

- Father of 8 year old boy

Consequences: “Autism is a Tragedy”

- Parents are pitted, often judged
- Professionals feel they have to “rescue” the child and family - believe they have all the answers.
- Professionals may not know how to talk about autism in a more balanced way, with a sense of humor (when appropriate), and looking at the cup “half-full”.
- Professionals may believe that the number one concern for the parents is the child with ASD, when in reality, they have many other issues to focus on in their lives.

Steps to refute “Autism is a tragedy” belief

- Understanding
  Professionals and the media convey the position (“autism as tragedy”), but parents crave hearing the position, as do students

- Compassion
  Understand how it feels to hear mostly challenges, parents may feel they are being blamed (even if not true), or feel that hope is taken away

- Appreciation
  Supporting parents by creating positive images of their child, and celebrating successes builds trust

- Support
  Understanding/valuing a student’s strengths as well as challenges provides a more realistic, balanced perspective

Actions that schools can take

- Celebrate success and “show off” abilities of students with ASD
- Talk about famous, accomplished people with ASD (Temple Grandin, Albert Einstein, Ms. Montana)
- Share positive stories from the media
- Invite parents of graduates to share their success stories

Myth

ASD is only within the child – the disease model of ASD

Progress - changing the behavior of the person – how person behaves and fits in

Goal is to approximate some what we call normal (but “normal is a setting on a dryer”), typical, etc.

Consequences: “ASD is only within the child”

- We set goals to change students, not for us to reflect on and change what we do.
- If a student does not make progress, it is either his or her fault, or the parent’s fault, because after all, we professionals are following “the program”
- We do not provide appropriate supports. The burden is on students with ASD, & if they do not make progress, it is their fault, or their families’ fault; the child is just so “impaired” that there is little potential for growth.
What we’ve learned - ASD is a shared HUMAN Experience

Becomes part of the fabric of life for all involved

Educators    Families    Those with ASD

Steps to understand autism as a “Shared Human Experience”

- Understanding
  Reflect on how autism is influencing your life - include both positive and challenges.

- Compassion
  When we feel challenged or frustrated, imagine how parents, family members, and the person with ASD feels.

- Appreciation
  When we celebrate successes, it should be a celebration for all.

- Support
  “Read high expectations for people with autism, but with appropriate, and when necessary, high levels of support.” —Barry Prizant

Actions that schools can take

- Focus on the behavior and attitudes of all staff, not just the student.
- Understand the positive impacts of a student on other students and the community in general.
- Accept the obligation for changes on our part, not just the student or parents.
- Communicate and model that the student is a valued member of the school community.

Why a Uniquely Human Perspective?

A deeper understanding of ASD builds trust with students and families
Makes our communities more humane and caring
Makes us all better people

For More Information & Resources

“I love his approach.”
-Temple Grandin, Author of “The Autistic Brain”

“Read this book. It’s a masterpiece!”
—Carol Gray, Developer of Social Stories

www.2187.com

barryprizant.com
twitter.com/BarryPrizant1
facebook.com/BarryPrizant
What to Expect Next

PresenceLearning will email you in the next few days:
- Certificate of Attendance for all attendees
- Link to the recording of the webinar & follow-up materials

For ASHA CEU credit, PresenceLearning will submit:
- Webinar participation information to ASHA for people who have provided valid ASHA membership ID & contact info
- CEUs may take 4-6 weeks to show up in your ASHA account
- No further action required on your part!
- Send CEU questions to ceu@presencelearning.com

For a demo or quote for PresenceLearning services
- Email us at school@presencelearning.com

COMING SOON

“Greatest Hits” Summer Self-Study Webinars
- A collection of our highest rated webinars including:
  - Temple Grandin, Julie Weatherly, Ron Caulder, Frances Stetson and many more
- Available for ASHA CE credits
- Prepare yourself to address challenges in the upcoming school year

plearn.co/greatest-hits-2015

The Leading Provider of Live Online Therapy Services for K-12 Students